

X-PM-Identity: <Default>
From: "Chris G. Brown" <cbrown@sandyhill.on.ca>
Organization: Sandy Hill Web Services
To: bob_culbert@cbc.ca
Date: Mon, 25 Oct 1999 01:04:53 -0500
Subject: Upcoming CBC TV Doc on MCS
Reply-to: cbrown@sandyhill.on.ca
BCC: (Suppressed)
Priority: normal
X-mailer: Pegasus Mail for Win32 (v3.01d)

The following is important context for any journalism concerning government and environmental sensitivities, environmental illness, or multiple chemical sensitivities.

These days authorities are using confusion around the sub- group with MCS to eclipse the issues and history of the larger group, people with all kinds of environmental sensitivities. Consumers supporting the MCS paradigm help abusers hide the existence of methods of assessment of sensitivities which are covered by OHIP and officially mandated recommendations to protect the larger group (including the subgroup with MCS) from damaging acts of commission in the health care system.

People who are not diagnosed because of attitudes are being subjected to treatments and environments that increase disability, cause worse illness, etc. People who are not being diagnosed are being abused by acts of commission that abusers hide behind debate about supposedly "new" problems.

Sometimes people who claim to have something they call MCS--a set of symptoms which is really several diseases that cannot be universally distinguished from each other or from other forms of sensitivities--legitimize the abusers' position that sensitivities are new when they are not. Neophyte activists are actually helping abusers pretend that they don't know things that in fact they do know.

Unfortunately, the drs of env med are better at medicine than they are at understanding how to frame issues, community dynamics, and worse, they have put acceptance of their theories and approaches, which fewer than half of people with multiple sensitivities subscribe to (despite what their fan club says) ahead of ending the ongoing abuse of all people with sensitivities.

At first patients think their lot is the same as that of drs of env med, but if you check around you will find that most people (Bruce Small, Ed Lowans, Lynda Brooks, and every past president of the Ottawa Branch of AEHA) graduate from that position. It is called the "demedicalization of disability" in the cross-disability movement.

Acceptance of phenomena is not the same as acceptance of an approach to dealing with them. There is reason to criticize some aspects of what doctors of environmental medicine do, for instance, while not denying or evading the reality of sensitivities.

One of the things that has set us back most is the demand, by drs of env med and their supporters, for a "standard treatment" when everyone who has been around for more than six months understands that there cannot be a standard treatment when you are dealing with a "compendium of disorders", any more than there can be a single physiological marker. (Quote is from an internal document at Health Canada in late 1980s, when they were actually helping, before the term MCS was being used to pretend that these problems are new.

Here's the Brief:

The Canadian Government and Environmental Sensitivities [Revised September 25, 1999]

Since 1980, I have worked to end the physical and emotional mistreatment of persons with central nervous system problems caused by physiological reactions to substances to which they are sensitive. Persons with psychiatric problems that are caused or significantly exacerbated by sensitivities are being hurt in Health Canada facilities, throughout the health care system, and in the community at large. It would appear that the main prerequisite to ending the mistreatment is an acknowledgement that what is taking place actually does constitute mistreatment. This acknowledgement may provoke feelings of liability and shame considering the fact that Health Canada has and is promoting misconceptions that cause the abuse.

Persons with central nervous system (CNS) symptoms caused by reactions have probably existed since creation. According to the June, 1980 Psychiatric Journal of the University of Ottawa, medical literature dates back three hundred years, to 1700. The literature indicates that reactions may be caused by a wide variety of different deficiencies, diseases, injuries and naturally occurring anomalies of physiology. Clinical experience dates back, at least, to 1880, with the main treatment being the avoidance of substances to which the person is sensitive. Recent work in Nova Scotia and by CMHC and others indicates that somewhere between three and thirty per cent of the population are prone to significant illness and disability as a result of environmental sensitivities.

Persons with CNS problems caused by sensitivities suffered greatly in the 1960's, 1970's, and 1980's as a result of hostility throughout medicine towards the theories of physicians who called themselves "clinical ecologists". Clinical ecologists claimed to understand and to be able to treat patients whose reactions were not strictly allergic in nature. Unfortunately, while they did help some patients, the medical explanations put forward by some clinical ecologists were overly simplistic, and alienated other physicians and scientists.

The only knowledge many physicians have of non-allergic sensitivities is of the extremely strong criticism of theories put forward by some clinical ecologists. Criticism of theory and clinical approach is too often mistakenly assumed to constitute an outright denial of the existence of the phenomena. A backlash to the theories of "clinical ecology" resulted in mistreatment, sometimes abuse, of persons with environmental sensitivities, and has delayed the protection of those persons whose CNS problems are caused or exacerbated by sensitivities and of persons with other health problems where undiagnosed sensitivities are a factor.

Another factor contributing to the abuse of persons with sensitivities was the arbitrary presumption, on the part of Health Canada and others, that sensitivities are usually caused by psychological factors. A public servant's office building sickness was dismissed as psychological by a Health and Welfare "handwriting expert". Patient complaints are often dismissed as being "all in the mind". Former Ontario Human Rights Commissioner Catherine Frazee described this practice as "placing the presumption on the wrong side". A damaging presumption is made on the expressed basis of an absence of information, on a lack of understanding of the various physiologies involved, against three hundred years of science and generations of experience among hundreds of thousands of citizens on all continents.

As a result of attitudes in medicine and other institutions, persons have been subjected to medical treatments which, because of their sensitivities, have actually increased their illness and disability.

Attitudes have contributed to other damages. Families have broken up when one spouse was advised that the other's problems were "all in the mind". Careers have been ruined when persons with sensitivities were mislabelled as malingerers. There have been suicides of persons whose lives became impossible to manage when people close to them refused to accommodate their special needs.

In 1984, then Ontario Health Minister Keith Norton appointed Judge George Thomson and five teaching hospital physicians to look into the problems faced by persons with sensitivities and to produce a report. Their report, presented to the Ontario government in 1985, noted that there are means of assessing persons with sensitivities that are covered by OHIP, and stated that the position "all the identified patients are emotionally ill" was "clearly untenable". Avoidance was indicated as a treatment. Attitudes among professionals on all sides were named as a problem.

In the late 1980's, Dr. Bruce Halliday, an MP from Oxford (Ontario) who had been named Canadian "Family Physician of the Year" in 1978, helped us greatly. Dr. Halliday was Chair of the Parliamentary Standing Committee on Health and, later, he chaired the Parliamentary Standing Committee on Human Rights and the Disabled. While Perrin Beatty was Minister of Health, Dr. Halliday encouraged helpful forces within Health Canada, and progress was made. In 1990, Health Canada organized a conference, and the proceedings were distributed to 20,000 physicians and to relevant provincial ministries and federal government departments. A key recommendation was that persons with sensitivities should "not be dismissed as neurotic, but receive respect and support".

A 1989 New Jersey government study about sensitivities won a Macedo Award from the World Health Organization. It again pointed out that some symptoms caused by sensitivities can also be caused by other illnesses. The authors (Ashford and Miller) recommended that, in ambiguous cases, sensitivities should be ruled out before the patient is subjected to treatments or environments which, if the problem were caused by sensitivity, could exacerbate illness, disability and socio- economic problems for the patient. Partly as a result of this study, Dr. Halliday was able to encourage Health Canada to organize a second conference about one high risk group, about sensitivities and psychiatric implications. Perrin Beatty, staff in Health Canada (except, notably, the Director of the Mental Health Division) and subsequent health ministers in the Mulroney government supported this recommendation and distributed it to a number of relevant agencies concerned about persons with CNS problems.

I thought we were out of the woods, and I left Ottawa to work. Unfortunately, after the 1993 election we were back to square one. The election cleared out a lot of the significant political support and, coincidentally, the file was assigned to a new staff person at Health Canada, someone who was unaware of our history, of the issues, or of the position of mainstream medicine. Apparently having heard the criticism of the theories of clinical ecologists, he was hostile to the point of being irrational. For instance, he claimed that the literature about environmental sensitivities was "only recent", then admitted he had only looked back to 1985. (Literature dates back to 1700. A Health Canada publication in 1987 listed literature back to 1908.) He met with people at CMHC who research the implications of sensitivities in housing design and construction and told them he would "shut you down" because "it's a crock". He trivialized the issue at international conferences.

Health Canada contracted research to identify a single physiological marker for sensitivities when they knew that task is impossible due to the fact that, as several internal documents state, a "compendium of disorders" are involved. Poor science produced predictably "inconclusive" results, but helped sustain the smokescreen of pretended good intentions which hides previous and current abuse.

Thirty-two MPs and senators, many of whom had been supportive while in opposition, approached health minister Diane Marleau. Only two received replies. The replies gave no indication that recommendations had been made to stop approaches that were causing child abuse, deaths, and the other damages mentioned above. The department reverted to the practice of discussing sensitivities as if they were an entirely new phenomenon, falling into a "single new disease" paradigm. Their position was reinforced by neophyte activists and MPs who were unaware of our three- hundred-year history, the compendium of disorders involved, or the work Health Canada had done prior to 1993, and who were dedicated to a limited interpretation of the approaches of clinical ecology.

My Member of Parliament set up a meeting with an assistant to David Dingwall when he became Minister of Health. A couple of weeks later a memo from Health Canada management directed staff to connect more positively with the work being done at CMHC. Still, nothing was done to protect persons with sensitivities from inappropriate treatments, to screen them out of high risk groups (persons with ambiguous symptoms) and protect them from measures that could, if their problem is exacerbated by sensitivities, cause increased illness and disability.

Staff in the office of the Leader of the Government in the Senate helped arrange a meeting with an aide to Allan Rock when he became Minister of Health. The meeting produced no visible action in the department. We then met with an aide in the Deputy Prime Ministers' Office. She seemed to understand that Canadians were being hurt because recommendations to protect them were being ignored. I believe she tried to help but ran into a brick wall when she approached Health Canada, and even in her representations to Mr. Gray's Executive Assistant.

In December 1998, I met with the Health Policy Analyst with the Privy Council Office. She was on an exchange from Australia, said that the issue was far further forward there, but seems to have come up against a brick wall as well. Nothing has been done to ensure that persons with sensitivities are screened out of high risk groups so that they will not be subjected to treatment that could cause increased disability or to attitudes that result in abuse and damages.

Many government officials are now discussing sensitivities as if they were a new illness resulting from "the modern environment". This approach eclipses the history of persons with environmental sensitivities. It obscures the fact that there exist both medicare-insured means of assessing such patients and official recommendations from mandated authorities to protect them from abuse.

The statement has been made over and over again, by sympathetic health officials, by political assistants, by lawyers working for the federal government, that liability for damages being caused is the main reason for a lack of forthrightness in dealing with this issue. In other words, because people are being hurt by the position Health Canada has and is taking, it is extremely inconvenient for the government to come clean and address the issue of ongoing damages that are being caused. So, while consumers were willing to set aside the issue of liability during the 1980s, it now seems to be a critical obstacle that must be faced if discussion is going to be honest, and if persons with undiagnosed CNS or other problems caused or exacerbated by sensitivities are to be protected from abuse.

While some officials are simply unaware of the facts, I believe it can be shown that some officials are making statements which they know are misleading and which they know are resulting in damages. Some are knowingly participating in a conspiracy of silence. Consequently, children are abused while adults are protected from being accountable for what is happening.

Scientist and researcher Dr. Michel Joffres, of Dalhousie University, once summed up a dilemma facing persons with sensitivities. An end to the abuse is in the hands of gatekeepers who are in a conflict of interest because they have caused damages in the past:

An important point is the fear of liability (at the legal and moral level) which perpetrates attitudes and actions. The protective psychological mechanism that comes into action when one knows deeply other people have been harmed, because of their negligence, or because they have been hiding behind the presumed lack of science, because they have minimized, belittled the issues, this mechanism which hides behind denial, camouflage, or aggression needs to be uncovered. Consequences need to be brought to the conscious level for healing to take place and prevention to take its role. Now people at governmental, industrial and academic level hide behind the oppressive properties of fear, fear of acknowledging what has happened.

Concerns about fraud causing child abuse and death require a lot more substantiation than can be provided in a short brief. I hope this gives you some idea of how political and financial liability is an obstacle to efforts of preventing the abuse of persons with central nervous system problems caused by environmental sensitivities.

I am not seeking damages for myself, and do not consider myself among those who are being horribly abused. The most horribly abused are not diagnosed.

I will continue to document and encourage the process of bringing an end to the Canadian government's actions, which officials know are causing child abuse and deaths, which serve to cover up the fact that they previously caused child abuse and deaths through mistakes and negligence, to persons with sensitivities.

Chris G. Brown
chris@storm.ca